

Copayment Foundations: Help for the Underinsured

BY TINA SHAH, MD

With focus often placed on the uninsured, many patients who are underinsured fall through the cracks. Copayment foundations look to fill their gaps in coverage.

Healthcare is an everyday topic of discussion in the media, and although discourse typically centers on which coverage strategies will be most effective — e.g., increased spending to provide universal coverage versus a shift in authority to the private sector — the plight of the *insured* often is overlooked. The fact is that the insured often are underinsured, and the number of Americans in this position is expected to continue to grow.

Why is it that the insured often find themselves struggling to pay for treatment, and sometimes are at a greater disadvantage than those with no insurance? Ironically, one reason is due to advancements in medicine. In the past decade, the biotechnology field has soared with novel drugs for treating numerous diseases, but with that came considerably higher health insurance premiums. Employers found themselves stuck in the middle; the technology to treat their employees had been developed, but the price of therapy and the cost of good health insurance were too great. That re-

sulted in cost shifting and considerably higher out-of-pocket costs for patients.

To meet the need for alternative funding, copayment foundations (CFs) were created to serve as a band-aid on a wounded and inadequate healthcare system.

DISEASE-BASED ASSISTANCE

CFs have been in existence since the late 1980s, but have been largely underused due to lack of knowledge about their existence. Yet they have great potential benefit to employers. As the name implies, CFs provide financial assistance for copayments (and sometimes, other expenses) to patients with diseases with high therapeutic costs, including cancers, chronic disorders, and rare conditions. Unlike a pharmaceutical-sponsored patient assistance program that is limited to those who have no insurance and to treatments manufactured by a specific company, CF charities are disease-based. Patients can obtain assistance for first-line treatments regardless of manufacturer, can receive aid for multiple drugs from one organization, and can benefit from a seamless transfer of funds

when therapy is changed. The return on this short-term assistance can be astounding for employers, who experience less absenteeism and employee turnover when experienced workers stay healthy and on the job.

The CF movement arose due to a combination of changing government laws and expensive biotechnological advances. The field of oncology was affected most significantly with the emergence of biotherapeutics to treat cancers. Given the highly disparate out-of-pocket costs compared to other diseases, insured cancer patients struggled finan-

cially. Oncologists subsidized treatment costs with the help of the pharmaceutical industry as they increasingly prescribed a company's product for more patients. This practice became illegal when the U.S. government enacted the Medicare and Medicaid Patient Protection Act of 1987. The "antikickback statute" made it a criminal offense to knowingly and willingly offer payment, to solicit, or to receive any remuneration in reward for referrals that are reimbursable by a federal healthcare program. Pharmaceutical companies thus were encouraged to make donations



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Table
Characteristics of several copayment foundations

Name	Founded	Patients served	Dispensed funds (\$)
Caring Voice Coalition ^a	2003	24,864 since inception	11,000 in 2006
Chronic Disease Fund ^b	2003	24,000+ since inception	NA
HealthWell Foundation ^c	2003	50,000+ since inception	44,000,000 in 2007
National Organization for Rare Disorders (NORD) ^d	1983	NA	9,000,000 in 2006
Patient Access Network (PAN) Foundation ^e	2004	25,000+ since inception	29,788,253 in 2007
Patient Advocate Foundation ^f	1996*	12,000+ since inception	12,235,123 in 2007
Patient Services Incorporated ^g	1989	Approximately 10,000 in 2007	17,756,169 in 2006

*Patient Advocate Foundation has been a copayment foundation since 2004.

NA=not available.

Sources: ^aPamela Harris, written communication March 2008, ^bChronic Disease Fund 2008, ^cHealthWell Foundation 2008, ^dNORD 2006,

^ePAN Foundation 2008, ^fPatient Advocate Foundation 2006/2007, ^gPSI 2006.

to not-for-profit organizations. Today, the pharmaceutical industry is the major financier of CFs, leading to what some view as a questionable relationship between the two: The industry serves as philanthropic “do-gooder,” enabling CFs to provide funds to patients for the purchase of pharmaceuticals, while receiving a sizable tax benefit for it.

The earliest CF was formed to provide assistance to patients with multiple sclerosis. In 1989, Patient Services Inc. (PSI) initially offered financial assistance to 52 MS patients (PSI 2006). This number has grown exponentially, with nearly 10,000 patients with various diseases served in 2007 (Table). PSI provides assistance with premiums, including COBRA payments, along with copayment assistance, and even pays for medical testing and other expenses not covered by its main programs. Today, several other CFs encompass a broad range of diseases and dispense more funding than ever imagined. Although these organizations share not-for-profit status and provide copayment assistance, they vary in size, disease focus, and other forms of aid.

The two largest CFs, as based on the amount of funds dispensed and the number of persons served, are the HealthWell Foundation (HWF) and the Patient Access Network (PAN) Foundation. Since their inception in 2003, these organizations have helped more than 50,000 and 25,000 insured patients, respectively (HWF 2008, PAN 2008). HWF provides aid for people who have one or more of 25 different diseases, including asthma and breast cancer. Assistance to counter the cost of treating the side effects of medical therapies, such as chemotherapy, is included. The PAN Foundation supports 20 different diseases.

PATIENT-CENTERED

Some of the organizations profiled in this article extend coverage beyond copayment aid to include deductibles, transportation costs, and medical devices not covered by insurance.

CFs use a streamlined, patient-centered approach to provide services. In general, patients must provide proof of insurance or of eligibility for insurance, and proof of a need for the medications or ser-

vices within the diseases funded by a CF to start the assistance process. Patients may receive funding from more than one foundation simultaneously. When money in a particular fund is depleted, CFs work to find alternative sources. Income also may be factored into eligibility; for example, the National Organization for Rare Disorders (NORD) has a cutoff of 300–500 percent of the federal poverty level (NORD 2006). Such cutoffs differ among and within CFs because of other considerations; for instance, NORD considers the impact of monthly household expenses in addition to medical bills, and the Caring Voice Coalition considers family size, number of children in school, and extenuating circumstances (Harris 2008). Turnaround time from application to aid is fast, simplified by counselors who work with patients on specific needs.

The financial support of these charitable organizations rests on their ability to accumulate funding to shield patients with inadequate insurance coverage from exorbitant out-of-pocket medical costs. CFs seek out various sources for dona-

tions including individuals, grants from such organizations as the Robert Wood Johnson Foundation, and collaboration with state government programs. The pharmaceutical industry, however, remains the largest donor to CFs, contributing roughly 90 percent of PSI's funding and 95 percent of the PAN Foundation's funding, for example (PSI 2006, PAN 2008). Although the antikickback statute outlaws the earmarking of industry gifts for specific medications, donors can designate funds for a specific disease that may, coincidentally, have only one or two drug options.

ETHICAL CONSIDERATIONS

Some newer CFs have been criticized for stretching the limits of their legal relationships with drug companies, and thus being *de facto* for-profit entities. The two largest CFs, HWF and the PAN Foundation, were created by independent, for-profit healthcare consulting companies. New Jersey-based Covance provides comprehensive drug development services including "launching and marketing a drug" (Covance 2008). In 2003, Covance helped to launch HWF, providing additional services and administrative personnel who still remain on Covance's payroll. However, HWF has IRS-designated 501(c)(3) not-for-profit status. The Office of the Inspector General of the U.S. Department of Health and Human Services has issued specific guidelines for these foundations, deeming them allowable as long as there is a distinct firewall between business and the foundation (DHHS 2004).

Support from any company, pharmaceutical or otherwise, provides advantages and disadvantages to other CFs and to patients. The PAN Foundation works in associa-

tion with Lash Group, a healthcare consulting company that focuses on Web-based support and other services to resolve issues with patient support and education, billing, and reimbursement for medical products. Lash Group provides technical support and Web site development for the PAN Foundation. This reduces the foundation's overhead — such costs accounted for 2.9 percent of the foundation's operating costs in 2007 — and allows a larger percentage of donations to go directly to patients in need (PAN Foundation 2008). In comparison, administrative costs absorb 10–20 percent of donation monies of other CFs (NORD 2006). Although there are regulations for 501(c)(3) organizations, clear variations exist between these CFs in practice.

The larger question is, how will CFs affect American healthcare? The PAN Foundation (2008) estimates that CFs address only 10–15 percent of the financial-assistance needs of the insured. The baby boomer population is aging will live longer with chronic diseases. Medicare Part D leaves a donut hole in the coverage for those who are insured. Novel drugs enter the market with high prices, many with protection from competition through orphan drug status. Factor in the potential for healthcare reform, and the only certainties are that the number of people without adequate insurance will continue to rise and that the need for CFs will remain.

It may be difficult to be completely comfortable with certain CFs having not-for-profit status. Such status allows biopharmaceutical companies — the largest contributors to CFs — to gain huge tax deductions. At the same time, however, CFs dispense millions of dollars in funds to patients, enabling

more people to pay for expensive medications. These are important considerations in any discussion about ethics.

CFs can help to defuse this issue by striving to decrease their dependence on pharmaceutical industry funding, partnering more with state programs and investing prudently. Concurrent changes in the financing of healthcare may ultimately improve coverage of the underinsured by encouraging a cost-effective model of healthcare delivery.

Until then, perhaps CFs should be considered a godsend, regardless of their financiers.

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Disclosure

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